DOCUMENT RESUME

ED 475 959 PS 031 214

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TITLE	Addressing Child Care Challenges for Children with Disabilities: Proposals for CCDBG and IDEA Reauthorizations.
INSTITUTION	Center for Law and Social Policy, Washington, DC.
PUB DATE	2003-02-24
NOTE	12p.
AVAILABLE FROM	Center for Law and Social Policy, 1015 15th Street, NW, Suite 400, Washington, DC 20005. Tel: 202-906-8000; Fax: 202-842-2885; e-mail: info@clasp.org; Web site: http://www.clasp.org. For full text: http://www.clasp.org/DMS/Documents/1046108337.25/clasp_ES.pdf.
PUB TYPE	Reports - Descriptive (141)
EDRS PRICE	EDRS Price MF01/PC01 Plus Postage.
DESCRIPTORS	Change Strategies; *Child Care; *Disabilities; *Financial Support; State Federal Aid; Young Children
IDENTIFIERS	*Child Care Needs; Child Care and Development Block Grants; Individuals with Disabilities Education Act; *Reauthorization Legislation; Subsidized Child Care Services

ABSTRACT

Families with children with disabilities often have difficulty finding high quality child care for their children; this problem is compounded for low-income families. In 2003, Congress will consider the reauthorization of the two statutes that support the development of young children with disabilities and their families-the Child Care and Development Block Grant (CCDBG) and the Individuals with Disabilities Education Act (IDEA). This paper discusses the benefits of providing quality child care and early intervention services to children with disabilities, and proposes recommendations for CCDBG and IDEA reauthorizations. The paper first examines how quality early intervention and preschool services for children from birth to age 5 help identify and address cognitive, physical, and emotional disability at young age, and how such services can work together to ensure that the child receives high quality care that supports his or her development as well as enabling parents to work and support the family. Next, the paper explores the challenges families face in finding child care services for children with disabilities, including the inability or unwillingness of many providers to accept such children, transportation and other logistical problems, and the scarcity of appropriately trained caregivers. The paper then provides background on DDCBG, IDEA, and other relevant statutes, as well as the children they serve. This section notes that need for increased federal funding has become critical in the wake of fiscal distress among state budgets. Finally, the paper offers recommendations for CCDBG and IDEA reauthorizations, focusing particularly on issues related to children with disabilities. Recommendations include the following: (1) increase mandatory funding for CCDBG; (2) require states to provide assurances in their state plans that they are making efforts to improve access to and quality of child care services to low-income children with disabilities; (3) amend the IDEA's Individualized Family Services Plan (IFSP) to require a statement of the child care needs of the family; and (4) amend the comprehensive system of personnel development under Part C of the IFSP to include child care providers and directors of programs that service children with disabilities and to train Part C service providers to work in partnership with other caregivers in inclusive group settings. (Contains 10

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Easter Seals

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Addressing Child Care Challenges for Children with Disabilities: Proposals for CCDBG and IDEA Reauthorizations

By Katherine Beh Neas, Easter Seals
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February 24, 2003

Introduction

Families with children with disabilities often have difficulty finding high quality child care for their children. This problem is compounded for low-income families for whom it can be a real struggle to find affordable, quality child care for any child.

This year, Congress will once again consider the reauthorization of the two statutes that support the development of young children with disabilities and their families—the Child Care and Development Block Grant (CCDBG) and the Individuals with Disabilities Education Act (IDEA). Together these laws provide the resources for the early childhood education infrastructure for young children with disabilities in all states. This paper discusses the benefits of providing quality child care and early intervention services to children with disabilities; describes the challenges families face in finding appropriate, high-quality child care for children with disabilities; provides background on CCDBG, IDEA, and other relevant statutes, as well as the children they serve; and proposes recommendations for CCDBG and IDEA reauthorizations.

The Benefits of Providing Quality Child Care and Early Intervention Services to Children with Disabilities

Quality early intervention and pre-school services for children ages 0 to 5 help identify and address cognitive, physical, and emotional disabilities at a young age. Ensuring that child care agencies and programs are connected with early intervention and special education services is critically important because, for some children, a child care setting might be the first opportunity for a childhood disability to be identified. Once a child's disability has been identified, child care, early intervention, and pre-school programs can work together to ensure that the child receives high-quality care that supports his or her development as well as makes it possible for his or her parents to

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work and support the family. Appropriate child care often means the difference in a child's getting a good start in life and a parent's keeping a job and achieving economic self-sufficiency for the family.

The Challenge of Finding Child Care Services for Children with Disabilities

However, finding care for a child with a disability is challenging for parents across the income spectrum. A mother of a child with a disability described her experience before and after she found appropriate child care:

> *Day care after day care was filled with people who had no experience with disabled children, no fault of theirs. The last day care, our third or fourth program, I remember I would pick up my son and listen about what art projects and things the other children did all day. The only report I would hear about my son was whether he did or didn't cry all day.*
>
> *This year, my son is enrolled at the Easter Seals Child Development Center in Montana. The Christmas program was an extremely tearful and happy event for us. Last year, my son cried with little participation. This year, he was running around the stage, Miss Kathryn took his hand, sat him on her lap and helped him participate. He sang almost the entire program. My son is now happy and participates.*[1]

Why is finding care for children with disabilities so difficult? The National Academy of Sciences' landmark report, *From Neurons to Neighborhoods,* identifies the main barriers identified by researchers that families face in accessing quality early childhood services:

> *Like all families with young children, those whose children have a disability or special health care need are faced with the challenges of finding good quality affordable child care. But the inability or unwillingness of many child care providers to accept children with disabilities, transportation and other logistical problems, difficulties with coordinating early intervention and child care services, and the scarcity of appropriately trained caregivers ... made the effort to find any child care a tremendous challenge for these families.*[2]

A Maine survey of child care providers confirms these conclusions. The survey found that only about one-third of the surveyed providers served children with medical, physical, or behavioral needs and 12 percent of the providers reported that they had not enrolled a child because of the child's behavioral needs.[3]

These problems are compounded for low-income families for several reasons. First, low-income children are more likely to have disabilities than children in higher income families. In 2000, 3.6 percent of children between the ages of 0 and 4 with family income below the poverty level and 10.5 percent of children between the ages of 5

and 17 below poverty had an activity limitation due to chronic conditions; for families with incomes above the poverty level, 3.2 percent of 0 to 4 year olds and 7.1 percent of children between the ages of 5 and 17 had an activity limitation due to a chronic condition.[4] A 2000 report on California welfare recipients in 1992 and 1996 found that almost 20 percent of the families had at least one child with a disability or illness.[5] Second, low-income families are more likely to live in neighborhoods that lack child care for children with special needs, as well as infant care and non-standard-hour care generally.[6]

The Federal Laws That Govern and Fund Child Development Services for Children with Disabilities

Two major federal programs provide resources to form an inclusive child care and early education infrastructure for low-income children with disabilities—CCDBG, a joint federal- and state-funded program that provides child care assistance to low-income working families, and IDEA. In addition, Section 504 of the Rehabilitation Act of 1973 (Rehabilitation Act) and the Americans with Disabilities Act (ADA) prevent discrimination against children with disabilities by child care providers. These laws are described in detail below.

Currently, neither CCDBG nor IDEA has sufficient funding to serve all eligible children. In FY 2000, only one of seven children eligible for CCDBG under its federal eligibility standards received child care assistance.[7] Similarly, states struggle to provide the appropriate level of services to children eligible for services under Part C and Section 619 of IDEA. The need for increased federal funding for CCDBG and IDEA has become critical in the wake of the fiscal distress most states are experiencing—over $60 billion in state deficits for FY 2003 and a projected $70 billion to $80 billion deficit in FY 2004.[8]

Child Care and Development Block Grant (CCDBG)[9]

The 1996 Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) consolidated four formerly separate child care subsidy funding streams—the Aid for Families with Dependent Children (AFDC) Child Care entitlement (for AFDC recipients who were working or in education or training programs), the Transitional Child Care (TCC) entitlement (for families who were transitioning from welfare to work), At-Risk Child Care (a capped amount of funding for states to provide child care subsidies for low-income families who were "at risk" of having to go onto cash assistance), and CCDBG, which provided funding for low-income families in work, education, or training whose income was below 75 percent of state median income (SMI). Congress stated that the program rules of CCDBG would apply to the consolidated funds. In PRWORA, Congress also gave states the ability to spend funds from the Temporary Assistance for Needy Families (TANF) block grant, which replaced the AFDC cash assistance program, on child care. Additionally, states may transfer as much as 30 percent of their current year TANF funds to CCDBG, and as much as 10 percent to the Social Services Block Grant (SSBG), provided that the total amount transferred does not exceed 30 percent.[10]

In FY 2000 (October 1, 1999 – September 30, 2000), 1.75 million children received child care subsidies funded by CCDBG. We do not know how many of these children have disabilities. Under the post-PRWORA CCDBG rules, a child is eligible for a CCDBG-funded subsidy if he or she is: age 12 or under (or, at the option of the state, is under age 19 and has a physical or mental disability and is incapable of caring for himself or herself, or is under court supervision); in a family with income under 85 percent of SMI (which can be waived for children in protective services or, in some cases, foster care); and residing with a parent who is working or participating in education or training or a parent who is not working or participating in education or training if the child is receiving or in need of receiving protective services.[11] While states' 1999-2000 CCDBG State Plans show that most states have taken advantage of the option to cover children with disabilities who are between the ages of 13 and 19, HHS data show that few children between those ages actually received child care subsidies.[12]

States are required to spend a minimum of 4 percent of CCDBG mandatory, federal and state matching, and discretionary funds (including transferred TANF funds) on activities designed to improve the quality and availability of child care in the state. States have broad discretion in defining those activities. States may spend these funds on a wide range of activities, including funding resource and referral agencies, providing training and technical assistance to providers, improving monitoring of and enforcement of compliance with health and safety standards, improving provider compensation, and providing health consultations to child care providers.[13] Many states have used their quality funds on initiatives designed to improve access to and the quality of child care for children with disabilities and other special needs.

Individuals with Disabilities Education Act (IDEA)

IDEA has two main service programs for young children with disabilities (Part C Early Intervention Program for Infants and Toddlers with Disabilities and Section 619 Pre-School Program) and one program that supports professional development and technical assistance (Part D). IDEA's Part C supports developmental services for infants and toddlers, up to age three, and their families. More than 230,000 children participated in Part C in 2001. Part C has three primary goals: (1) to enhance the development of young children with disabilities, (2) to enhance the capacity of families to meet the special needs of their young children, and (3) to enhance the capacity of states to provide quality early intervention services. Young children and their families are eligible for Part C services if the child is under the age of three and experiences developmental delays in one or more areas of development or has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay. States also have the option of serving children at risk of developmental delay. Eight states currently serve at-risk children. Once a child is found to be eligible for Part C services, the state and the family develop an Individualized Family Services Plan (IFSP) that details the family's goals for the child and the services necessary for the child and family to achieve these goals. Most of the children who received Part C supports in 2001 were served in their homes or in a child care setting.

IDEA's Section 619 pre-school program provides special education and related services to preschool-aged children with disabilities. More than 598,000 children participated in the IDEA 619 preschool program in 2001, receiving services in public schools or child care, Head Start, or other settings. A child between the ages of three and five is eligible for Section 619 services if he or she has a disability and needs special education and related services. States have the discretion to also provide IDEA-funded pre-school services to children experiencing developmental delays (even if they do not have a specific diagnosis of a disability) and who need special education and related services. Once a child is found eligible, the local school district and the child's parents develop an Individualized Education Program (IEP) that details the specific education goals for the child and the services necessary to achieve the goals. In 2001, 53 percent of children enrolled in preschool special education received their services in settings with typically developing peers. Child care centers are among those settings. In some communities, a child who received Part C services in a child care program can also receive 619 services in that same setting. However, in other communities, a child who received Part C services in a child care program must move to a public school program once he or she reaches the age of three.

IDEA's Part D provides grants to create and support the special education infrastructure through research, dissemination, the application of research findings to instructional practice, parent training, and effective personnel preparation and technical assistance. The majority of these funds are distributed through competitive grants. Part D also supports State Improvement Grants, which assist states in meeting personnel needs and have been used primarily for in-service training.

Americans with Disabilities Act (ADA)/Rehabilitation Act of 1973(Rehabilitation Act)

ADA requires child care programs to accept children with disabilities and provide reasonable accommodations to ensure their participation. Almost all child care providers, except child care programs that are run by religious organizations, are subject to the provisions of Title III of ADA as public accommodations.[14] Furthermore, child care programs operated by government agencies are subject to Title II of ADA, which prohibits discrimination by recipients of state or local funding.[15] Finally, if a child care program accepts federal funds through such programs as the Child and Adult Day Food Program or CCDBG, the program is subject to Section 504 of the Rehabilitation Act, which prohibits discrimination against people with disabilities by recipients of federal funding.[16] Providers who are subject to these laws cannot discriminate against children with disabilities by refusing to serve them if serving the children would not pose a direct threat to others and would not require a fundamental alteration of the program.[17]

Recommendations for CCDBG and IDEA Reauthorizations

This year, Congress has the opportunity to increase the quality and availability of early childhood services through the reauthorizations of CCDBG and IDEA. The following recommendations are designed to build upon the early childhood infrastructure that these two statutes already support in the states. They focus particularly on issues

related to children with disabilities and do not represent all of the CCDBG and IDEA reauthorization recommendations of Easter Seals and the Center for Law and Social Policy.

Child Care and Development Block Grant

1. **Increase mandatory funding for CCDBG by $11.25 billion over five years.** The need for additional child care resources to expand access to and improve the quality of child care services is great. Currently, only one out of seven children who are federally eligible for child care assistance receives this assistance. Funding for quality initiatives is inadequate for badly needed systemic reforms, including initiatives targeted at children with disabilities and other special needs. Furthermore, without additional funding, states cannot set their provider payment rates at a level adequate to compensate providers for the cost of providing care for children with disabilities. Inadequate payment rates can make providers reluctant to serve children receiving subsidies, particularly children with disabilities or other special needs children.

   In the coming years, states will *at the very least* need significant additional funding to maintain their current level of services against inflationary pressures, as well as to serve the children of welfare recipients who may be subject to increased work requirements. However, states also need additional funding to broaden access to child care assistance for low-income families who are not welfare recipients.

   There is also a great need for additional resources for quality-building initiatives, which are not limited to children receiving child care subsidies. Researchers have pinpointed several aspects of care that could improve child outcomes for children—particularly for those of disadvantaged backgrounds—including improved licensing standards and enforcement, child-staff ratios, and teacher education, training, and compensation. States need increased resources in order to train providers about the social and emotional development and literacy needs of all children (while addressing the unique needs of children with disabilities and other special needs); to support providers with ongoing mentoring and other supports, including access to health consultants, resource and referral services, and specialists in disability and infant and toddler issues; and to increase providers' compensation to improve retention.

   Federal support for child care programs will be particularly important this year because the CCDBG and IDEA reauthorizations are occurring against the backdrop of a severe fiscal crisis in the states. This fiscal crisis has and will likely continue to put pressure on governors and state legislatures to cut services.

2. **Require states to provide assurances in their state plans that they are making efforts to improve access to and the quality of child care services for low-income children with disabilities.** First, the market rate requirements in the CCDBG Act should be strengthened. The current CCDBG equal access provisions have not been sufficient to assure equal access to quality care. States should be required to provide

assurances that they are basing their payment rates on statistically valid biennial market rate surveys. States should also be required to show that they are considering the cost of caring for children of all ages and disabilities in setting their provider payment rates.

Second, states should be required specifically to detail how the CCDBG lead agency collaborates with the state's IDEA Part C, Section 619 and Part D activities. Current fiscal constraints in states make it even more important that agencies work together to plan and implement policies and programs that maximize scarce resources. These collaborations can facilitate strategic planning across a state's early childhood programs and promote joint training, technical assistance, and other activities that will increase the supply and improve the quality of child care and early education opportunities for children with disabilities. This state plan requirement would make more specific the general CCDBG requirement that states consult with other early childhood agencies in developing their state plans and in providing services. By adding this requirement, Congress would be imposing on state child care agencies the same responsibility for collaboration that is placed on state disability agencies.

Third, states should be required to provide assurances that they are informing parents and providers of the requirements of ADA, the Rehabilitation Act and IDEA. Providers need to know what kind of care they must provide to children with disabilities. Parents need to know what their rights are to access child care and to expect that reasonable accommodations will be made to provide appropriate care for their children.

Individuals with Disabilities Education Act

Part C

1. **Amend the Individualized Family Services Plan (IFSP) to require a statement of the child care needs of the family**. The IFSP process requires a family to identify its resources, priorities, and concerns and to identify the supports and services necessary to enhance the family's capacity to meet the developmental needs of the child. More than half of women with children under the age of three are in the workforce. Given this fact, service coordinators should discuss with families their needs for child care services when developing IFSPs and should assist families in accessing appropriate services. This change would not require Part C to *pay* for child care services, only to assist families in accessing them. For example, Part C service coordinators could refer families to a state or local child care resource and referral agency.

2. **Amend the comprehensive system of personnel development under Part C to include child care providers and directors of programs that serve children with disabilities and to train Part C service providers to work in partnership with other caregivers in inclusive group settings.** Most training sponsored by Part C is directed to early intervention direct service providers, including occupational, physical, and speech therapy providers, not to early childhood classroom staff.

However, young children with disabilities increasingly have their IFSP services delivered in child care settings. In these situations, child care staff work in partnership with early intervention services providers to facilitate the children's development. Allowing child care staff to participate in the same Part C training activities as their other early intervention partners would greatly enhance these collaborations. Moreover, Part C direct service providers need to be trained on how to implement early intervention services in inclusive group environments that serve children with and without disabilities.

Section 619

1. **Amend the Individualized Education Program (IEP) to require a seamless transition for preschool children who are transitioning from Part C. This would require an explanation of the components of the child's IFSP that should be carried over to the IEP and a justification as to why such services cannot be continued in the setting in which they are provided under the IFSP.** When children with disabilities turn three, they lose their eligibility for early intervention services and become eligible for Section 619 pre-school programs. In many cases, these three-year-old children become the responsibility of a different state agency that handles the IDEA pre-school program, as opposed to the agency that handles early intervention services. As a result of this program and agency switch, children can lose both continuity of care and access to the services and supports they and their families received under their IFSP.

   In order to address this issue and promote a seamless transition for children and families, three states currently use IFSPs for all preschool children. Twenty-two states allow local discretion in using IFSPs for preschool children.[18] This flexibility allows some children to remain in the settings in which they received early intervention services after they have turned three, and their services become the responsibility of a new state agency. The same result could be achieved by requiring that the IEP plans developed for these children include explanations of what services from their IFSPs should be carried over and why such services cannot continue to be provided in the IFSP setting. This practice can help families who may continue to need the family-centered supports that are in their child's IFSP and are needed to facilitate their child's development but that the education system is not obligated to provide under section 619.

2. **Amend the comprehensive system of personnel development under Part B to include child care providers and directors of programs that serve children with disabilities, and to train Part B Section 619 pre-school service providers to work in partnership with other caregivers in inclusive group settings.** This recommendation parallels the Part C comprehensive system of personnel development recommendation for children served with Part B funding. Because section 619 is a part of Part B, this change would also apply to providers of services to pre-school children under section 619.

Part D

1. **Require states submitting a State Improvement Plan to include a description of how they will incorporate training for all early childhood professionals, including child care teachers and administrators, into their current programs; how such training will be coordinated with training supported by CCDBG; and how curricula will support training on providing services in inclusive group settings.** A state agency applying for an IDEA-funded State Improvement Grant (SIG) must submit a State Improvement Plan (SIP) that sets priorities for training and professional development activities directed at improving educational results for children with disabilities from birth through age 21. Seventy-five percent of SIG funds are currently directed to professional development activities. However, the majority of these grants do not address personnel issues for providers serving children ages birth to five. Requiring states to include training requirements for child care teachers and administrators and to incorporate training on the provision of services in inclusive group settings into their SIPs could better enable states to comprehensively review and address personnel needs for these providers.

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Endnotes

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[11] 45 C.F.R. § 98.20(a)(1) (2001).
[12] U.S. Department of Health and Human Services, Child Care Bureau, *Child Care and Development Fund: FFY 2000 Tables and Charts* (Washington, DC: HHS, June 26, 2002); U.S. Department of Health and Human Services, Child Care Bureau, *Child Care and Development Fund: Report of State Plans for the Period 10/01/99 to 9/30/01* (Washington, DC: HHS, April 2001), Appendix II.
[13] 45 C.F.R. § 98.51.
[14] See 42 U.S.C. §§ 12181(7)(K) (2001) (including "day care center . . . or other social service establishment" in the definition of public accommodations); 12182 (prohibiting discrimination in public accommodations); 12187 (exempting religious organizations and most private clubs from prohibition).
[15] See 42 U.S.C. § 12131.
[16] See 29 U.S.C. § 794 (2001).
[17] See 42 U.S.C. §§ 12182(b)(2)(A)(ii) & (3).
[18] Shelly DeFosset, ed., *Section 619 Profile, 10th Ed.* (Chapel Hill, NC: National Early Childhood TA Center, 2001).

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